

Emotional Experiences of Hiv-Positive Mothers: Care Implications

Richardson Augusto Rosendo da Silva¹, Modesto Leite Rolim Neto², Vera Maria da Rocha³.

ABSTRACT

This is an exploratory descriptive study with qualitative approach, where one searched to identify feelings and expectations of HIV-positive mothers when living the experience of care for their HIV-positive children. The sample was composed of eleven HIV-positive volunteer mothers, enrolled in the clinic of the reference public hospital for infectious illnesses, in the city of Natal/RN/Brasil. After the signature of a free and clarified assent term, data were collected by the application of a semi-structured interview, whose reports were recorded and transcribed literally. For analysis, it was used the technique of content analysis, creating categories that emerged from the proper speech. The prevalent categories in relation to the experience of care for an HIV-positive son were: protection; anxiety; fear; loss; separation; prejudice; doubt and hope. The condition of the mother as an HIV-positive herself was not evidenced as the biggest concern. Mothers prioritize the needs of the child and the care for the children and the family. These data reveal "a suffering" on the mothers which guides us for a better qualified attention, carried in a perspective of reinforcement of their self-esteem and self-care.

DESCRIBERS: AIDS, HIV, HIV-positive mothers, care for HIV-positive children.

INTRODUCTION

The epidemic of AIDS represents one of the most serious problems of public health in present time, presenting high degree of morbidity and mortality with perspectives of a continuous growth and spread in all continents. The possibilities of control of this disease still seem remote, despite the development of new therapies and the world-wide effort in the search of the cure against the infection¹.

With dynamic profile since its sprouting, the epidemic changed its transmission pattern, leaving risk groups as homosexuals, masculine bisexuals, injectable drugs users and receptors of contaminated blood for an increasing trend of heterosexual transmission. This change on transmission patterns makes one find a growing frequency of infected women and, therefore, a larger incidence of congenital AIDS^{2,3}.

¹Nurse, Master's Student, Postgraduate Program in Health Sciences - UFRN. richardsonaugusto@hotmail.com

²Psychologist, Professor at Universidade Federal de Campina Grande- UFCG; PhD in Health Sciences - UFRN. modestoleiterolim@bol.com.br

³Physical Therapist, Postgraduate Program in Health Sciences. PhD in Education - UFRN. vera@digi.com.br

According to data of the report published by ONUSIDA/OMS (2004) about HIV/AIDS world-wide situation, there is a ratio each time larger of infected women in a percentage that grows in all Eastern Europe, Asia and Latin America. Until December of 2004, there were 39.4 million HIV-positive people and, from this amount, 17.6 million were women⁴.

In Brazil during the period between 1980 and 2004 there were 362.364 diagnosed cases of AIDS; from this amount, 111,314 (30,7%) of the notifications mention the female gender. About pediatrics AIDS, in the same period there were 13,786 cases, reaching children under 12 years old from which 6.949 (50.5%) were male and 6.837 (49.5%) were female⁵.

At present, epidemiologic data show that approximately 85.0% of AIDS cases in younger than thirteen years old in Brazil are caused by vertical transmission⁶. This modality is becoming a great challenge for public health⁷, requiring new vigilance strategies, including vigilance of second-generation HIV infection, that incorporates on an integrated way, data related to the infection and the behaviors of feminine population^{8,9}.

AIDS turns infected people dependent of new habits because of the disease. These changes in their quotidian cause an adaptation reaction to demands in the family and in the patient and modify the relationship towards society¹⁰.

In most families, the mother is responsible to provide the care for the son, mainly the infected one, what creates a work overload. She has the responsibility of coordinating treatment and daily activities¹¹. The presence of an infected child can perform a change in the dynamics of interaction between HIV-positive mothers and their HIV-positive children and this relation tends to be full of fears, blames and suffering.

One intend, with this work, to contribute for a better understanding about the implications of AIDS in childhood; for a better relation between HIV-positive mothers with their infected children and

to awaken professionals for an integral attention to HIV-positive mothers.

OBJECTIVE

To identify and to describe feelings and expectations of HIV-positive mothers when living the experience of taking care of their HIV-positive children in the reference hospital for infectum-contagious diseases in Rio Grande do Norte/Brazil.

METHODOLOGY

This is a descriptive research with qualitative approach, carried in the clinic of Hospital Giselda Trigueiro (HGT), which is reference in the treatment of AIDS in the city of Natal – Rio Grande do Norte/Brazil.

The population was constituted of HIV-positive mothers with HIV-positive children attended in the reference center. The sample was composed by 11 mothers who accepted to participate voluntarily of the interviews, with the signature of a free and clarified assent term, obeying the following inclusion criteria: a) to agree to participate of the research as a volunteer; b) signature of a free and clarified assent term by the participants; c) to have medical diagnosis of HIV-positive confirmed; d) to be older than 18; e) to have, at least, one child with HIV-positive diagnosis confirmed; f) to be in consultation in the clinic of the Hospital on the day of the interview.

Exclusion criteria were: the non-signature of the assent term; mothers of children younger than 18 months, with diagnosis still not confirmed and mothers who, voluntarily, quit the study during the period of collection.

As collection instrument, it was used an interview with structured questions, previously evaluated by expert researchers in the theme and validated through a pilot study. The interview was

composed of open and closed questions based on intentions of this research and its bibliographical revision.

After authorization by the HGT Directory and approval of the project on the "Comitê de Ética em Pesquisas com seres humanos" (Ethics Committee in Human Research) of *Universidade Federal do Rio Grande do Norte*, nº 142/04, data collections were started and lasted from March until June/2005.

Interviews took place in a particular room of HGT during the consultation day of ambulatory attendance of the children, what happens once per month on Tuesdays or Thursdays mornings. Procedures followed ethical aspects from resolution nº 196/96 of the "Conselho Nacional de Saúde" (National Health Council) that regulates human research¹². Interviews were recorded and then completely transcribed and grouped in categories that emerged from the proper speech, according to

BARDIN's¹³ content analysis. Quantitative data were grouped in frequencies and percentages tables.

RESULTS

Results will be presented considering sample characterization and analysis of interviews with categories according to the questions made.

Participants' characterization

One interviewed 11 young HIV-positive mothers, between 20 – 36 age range (average: 28 years old). About scholarity, it was observed that the greatest amount of women did not complete primary education (6), corresponding to 54.5% of the interviewed ones; 3 (27,3%) participants have concluded primary education and only 2 (18,2%) attended secondary education, however they did not conclude it (Table 1).

Table 1 - Distribution of women with AIDS about scholarity according to age.

Variables Age (years old)	Solarity					
	1 ed. inc.		1 ed. comp.		2 ed. inc.	
	<i>n</i>	%	<i>n</i>	%	<i>n</i>	%
- < 20 -	-	-	-	-	1	9,1
- 20 25 -	-	-	2	18,2	1	9,1
- 25 30 -	2	18,2	1	9,1	-	-
- 30 35 -	3	27,3	-	-	-	-
- 35 40 -	1	9,1	-	-	-	-
Total	6	54,5	3	27,3	2	18,2

Natal, Hospital Giselda Trigueiro, March to June/2005.

Another analyzed aspect about the profile of the participants is related to marital status. One observed that amongst mothers, 2 (18,2%) were married, 3 (27,3%) were divorced and, the greatest amount, 4 (36,3%) were single mothers. There were, amongst participants, 2 (18,2%) widowers.

The *Hospital Giselda Trigueiro* is a reference center on the state of Rio Grande do Norte for attendance of infectum-contagious diseases patients.

It was observed, then, that amongst interviewed, 8 (72,7%) came from other towns while only 3 (27,3%) were from the capital (Natal). The prevalent familiar income in the studied sample was one minimum salary, 8 (72,7%) participants and 3 (27,3%) earned until two minimum salaries. At the time of the research, one minimum salary of reference was two hundred and sixty "Reais" (R\$260,00).

About work activities, the majority of participants (5; 45,4%) were housewives and also take care of their children. Other functions related

were: maid (2) and hairdresser. Amongst the participants, 3 (27,3%) were unemployed (Table 2).

Table 2 - Distribution of HIV-positive women about work activities according to age.

Variables		Work activity					
Age (years old)		Housewife		Employed		Unemployed	
		n	%	n	%	n	%
- <	20 -	1	9,1	-	-	-	-
- 20	25 -	-	-	2	18,2	1	9,1
- 25	30 -	1	9,1	1	9,1	1	9,1
- 30	35 -	2	18,2	-	-	1	9,1
- 35	40 -	1	9,1	-	-	-	-
Total		5	45,4	3	27,3	3	27,3

Natal, Hospital Giselda Trigueiro, March to June/2005.

According to interviews, the prevalent way of contamination was through heterosexual transmission (63,6%) through steady partner. Four women (36,4%) acquired HIV virus through the use of injectable drugs.

Major diagnosis concentration happened in 2001 (Table 4). Data about year of contamination allows the observation that 1997 and 2000 had one diagnosed case per year. In 2001, 4 (36,4%) cases amongst the participants were diagnosed. Between 2002 and 2004 also there was only one diagnose per year.

Expression of the feelings of HIV-positive mothers

As stated by the objectives of the present study, in this section some categories will be presented from mothers' speech during the interviews, according to guiding questions. In their talks, such feelings and expressions were reported: overprotection; fear; donation; anxiety; anguish; prejudice; doubts and hope. Some categories will be

presented and the prevalent ones will be detailed at discussion.

Overprotection and fear

One observed at mothers speech that the daily routine of an HIV-positive child is frequently marked by presence and risk of opportunistic diseases creates a feeling of protection and fear in mothers if their child suffer any violence for being HIV-positive. The disease appears as a constant threat and fear appears not only related to illnesses and death, but also for the expected prejudice and the uncertainty of future.

The following talks suggest such characterization:

"We, who are mother of an HIV-positive child, must protect him a lot all time, because children with AIDS fall ill much more". (Interview 9)

"I protect my son excessively, because I am afraid he suffers any violence for having this disease" (Interview 4)

"I am afraid my son will be abandoned in the future; how he will face the world? What he will be like?". (Interview 7)

Donation

The way how mothers express the donation feeling evidences certain guilty about their child's illness. However, one observed that their HIV-positive condition does not seem to be an important concern. In their talks it is possible to realize that their priority is children healthcare and for it they use all their potential, according to these sentences:

"I try to satisfy my son totally; everything is for him; I think I do this to relief my guilt". (Interview 1)

"To take care of my son is in first place; he takes all my time and energy; I can forget my consultation, but I do not forget his". (Interview 5)

Anxiety and anguish

Anguish and anxiety feelings are generated in the occasions where children fall ill or get immune protection worse, situation that is also related to an announced death. One observes in the following sentences:

"It is to live in anguish to know that one day I and my son will be separated; I don't know who will die first, but that we will be separated on Earth, this I know "(Interview 7).

Eminent possibility of separation between mother and child for the certainty of death, keeps emotions linked to anxiety and anguish feelings all time.

"Everybody knows that this disease takes to death; I take care of my son with love; I do everything for him; it is like a bird that prepares the nest for its babies; it is an anguish that we live; sometimes I cry thinking about dying and letting my son without a mother"(Entrevista 3).

Prejudice

Prejudice was seen as a present characteristic in the routine of life of the mother and her HIV-positive son, happening in the family, between neighbors and in the proper school of the child, being able to be related many times to lack of information.

"It hurts me to see my son sad and isolated when I arrive to catch him at school. While all children are playing, he is seated because the teacher said that he can get hurt in the plays and contaminate his mates " (Interview 2).

Despite experiences marked negative feelings, many interviewed used overcoming strategies and support to lead their lives and to keep "strength" to the care of herself and her children. Amongst these strategies, one distinguished religiosity and the expectation of cure for divine intervention or science advances. One detaches the categories faith and hope in the words of the participants.

Faith and Hope

To have faith in God and hope that one day it will be discovered the cure for this disease were manifestations of many interviewed mothers, which referred to these feelings as a way to live the AIDS and to support the anguishes and fears created by the routine of care and diseases. Reports below express this situation:

"My hope is in God, without faith I would not have strength to take care of my son. Only God can do something "(Interview 5).

"My expectation is in the cure of the disease; I have faith in Jesus that a vaccine will be found out to cure us; only this way I got used to this illness ". (Interview 1)

"I have a hope that one day I will see the cure for this disease, to see my son cured, then

desert will turn sea again, I will smile again; thus I forget the hard reality to live with this illness" (Interview 2).

DISCUSSION

Results about to the profile of volunteers made possible their characterization as young women, who have low scholarship and were contaminated between 18 – 22 years old. These data are similar to the prevalence of AIDS in women, during the period between 1980 and 2004 in Brazil¹⁵. Studies from *Ministério da Saúde* (Ministry of Health) point that 55.5% of 19 years old or more, HIV-positive women present as scholarship basic education incomplete¹⁴. Actual data from *Ministério da Saúde* indicates that the 90's concentrated major percentage of AIDS cases in reproductive age women (between 25 and 34 years old). In 2000 there was an increase of 15,2% of infected pregnant in comparison to 1980¹⁵. The present study demonstrates that 5 (45,4%) participants were contaminated between 2000 and 2001.

The increase of cases between heterosexuals characterizes what it has been called "feminilization process" of AIDS. In 1983, the number of cases notified in Brazil corresponded to a ratio of 40 men to 1 woman; from 1998, the ratio was 2:1, with strong trends to become 1:1¹⁶.

Some factors are pointed to a bigger female vulnerability to contamination for HIV in an unprotected sexual relation: viral load in sperm; major contact area (vaginal canal); sexual relation during menstrual period; presence of undiagnosed and asymptomatic Sexually Transmitted Diseases (STD) that certainly increases the risk of infection¹⁷.

As social vulnerability, mainly in poor countries, women are still obliged to live unequal relations, economic dependence and sexual submission. These questions turn difficult the adoption preventive practice to HIV and other STD's, because it involves negotiation with masculine sex

and requires a reflection about proper feminine sexuality that lived under silence and censure in the majority of the cases¹⁷.

About scholarship, data from *Ministério da Saúde* confirm that the lower school education, the greater is the probability of incidence of AIDS cases¹⁸, corroborating our findings.

One observed in the present study that 72,7% of participants are from towns outside the state capital. One assumes that many cases from the capital, by involving people with better financial conditions, individuals can be directed to other states. On the other hand, one observed that more frequently AIDS is getting into small towns in Brazil^{15,19,20}.

Data found in this study are corroborated by current profile of epidemic. In the 80's almost all cases were man infected by homosexual sexual transmission; in the 90's there is prevalence between poor people, women and heterosexual sexual transmission¹⁵. Fonseca²¹ carried through a study HIV-positive women and it indicated housewives as the main occupation related, as found in this study.

An important aspect to be considered is that women only find out about their HIV-positive diagnosis when they were pregnant and had started prenatal follow-up. Similar data were found by Stefani²². Other studies evidenced that diagnosis in women is more delayed than in men^{23, 24}. It is possible that such situation, still not accepted socially, increases the stigma of the HIV-positive women, making it more difficult confrontation with the disease²⁵.

Feelings and emotions

About interview data that tried to describe these women's emotions and feelings, mainly about the fact of having an HIV-positive child, one can evidence that overprotection and donation feelings; anxiety when the son falls ill or has to be submitted to a therapeutical procedure; anguish for the threat

of mother and son separation; prejudice; doubts and hope in the discovery of the cure of the illness were present in almost all speeches.

Irvin *et al*²⁶ affirm that parents concern about their child's future, guilt and unsolved anger cannot determine an overprotecting behavior. This exactly feeling, that means extreme goodness and patience, is evidenced in studies made with mothers of children with chronic diseases^{27, 28}. Despite the inevitable separation in some hospitalization situations^{11, 27}, in the universe of HIV-positive people, there is fear of falling ill and dying, permanently²⁹.

Sexual reproduction and children care still continue to be considered as part from feminine nature, such in education and prevention activities as also in healthcare organization³⁰. In low income families, whose difficulties are more frequent, care requires a lot of time and energy and it limits caregivers performance of other tasks³¹.

Emotional instability is a common feeling in HIV-positive people's life³². Mood constantly oscillates and daily experience with future death possibility is something that raises emotional instability. In this study, mothers presented anxiety and anguish feelings. About it, other studies show that HIV-positive people's fragility is remembered more frequently. These people are more susceptible to opportunistic infections and to meticulous use of medicines, many times per day, frequent medical consultations and complementary examinations, because an infection that used to be common, gets life and death value. Routine changes and distance of friends contribute for these feelings³². With regard to the son, loss threat and the sensation life ending, make the mother more vulnerable and anxiety feelings emerge in an intense way, therefore it happens the most complex thoughts ahead the invisible, undefinable and unexpected³³.

AIDS is a disease that deeply marks infected people, therefore it affects their physical, mental and social well-being and involves negative feelings as

depression, anguish and fear of death, interfering with their identity and self-esteem³⁴.

AIDS patient isolation is exacerbated by fears or rejection observed in healthy people, spouses, relatives, friends, work and school mates³⁴. With children, the experience at school environment many times appears as source of discrimination³⁵. In these situations, professors need to be informed to serve as emotional, material and informational support to the child³⁶ and its family.

As previously mentioned, despite the set of fears and anguish lived by mothers, in this trajectory there is an overcoming experience. In this aspect, love, faith, spirituality, hope, beliefs and other feelings are used as strategies for survival and renewal of positive feelings. In most part of the cases they give meant and sustentation for confrontation with the illness, changes and losses that accompany it¹¹. Hope, considered as a complex human experience, is presented as a sustentation force that assists people to avoid discouragement and to live longer in spite of any adversity³⁷.

Pinheiro described the experience of mothers of children with cancer, demonstrating that they presented a strong feeling of uncertainty and hope for the cure of this disease³⁸. In a study with mothers of children with chronic illness, it was observed that hope in a better life and free from the illness was a common report, where this hope was the strategy used as a way to face the disease and to keep searching treatment and cure¹¹.

CONCLUSION

Results made possible the conclusion that the volunteer mothers of this study were young, schooled and single.

For this group of interviewed women, aspects as youth, HIV-positive themselves and live the experience of taking care of their HIV-positive son, disclosed involved feelings as overprotection, donation, anxiety and anguish when the son falls ill

or needs to be submitted to a therapeutical procedure and for the eminent separation caused by mother's and/or son's death.

One can conclude that, despite the adversity, mothers keep feelings of hope and faith as a support for the lived situation.

The use of qualitative approach and content analysis technique used in this study to emerge participants subjectivity, within manifestation of feelings and doubts on taking care of a son with AIDS. For some of them, besides allowing identification and expression of their concerns, future expectations related to the illness, fears and real difficulties, it also allowed to share these emotions with another person, what is difficult of being done during attention in hospital services.

Finally, one expects that discussion of this subject contributes for a better understanding of the complexity that involves AIDS in childhood and in women and, that it stimulates professionals approaches based in sensitivity to attend integrally the needs of those who live with AIDS particularities.

REFERENCES

1. Ceccato MGB, Acurcio FA, Bonolo PF, Rocha GM, Guimarães MDC. Compreensão de informações relativas ao tratamento anti-retroviral entre indivíduos infectados pelo HIV. *Cad. Saúde Pública* 2004; 20(5): 1388-97.

2. Tomazelli J, Czeresnia D, Barcellos C. Distribuição do caos de AIDS em mulheres no Rio de Janeiro, de 1982 a 1997: uma análise espacial. *Cad. Saúde Pública* 2003; 19(4): 1049-61.

3. Vieira MFR. Tópicos relacionados com a infecção pelo HIV na gestação e infância. *Revista Bioética* 1993; 1(1). Brasília, conselho federal de medicina. Disponível em:
URL: <http://www.cfm.org.br/revista/bio1v1> [25ago. 2005]

4. ONUSIDA/OMS. Programa conjunto de las Naciones Unidas sobre el VIH/SIDA(ONUSIDA). Organización Mundial de la salud (OMS). Situación de la epidemia de SIDA; diciembre de 2004.

5. Ministério da Saúde (BR) Boletim Epidemiológico, Brasília (DF): Ministério da Saúde; 2004.

6. Ministério da Saúde (BR) Boletim Epidemiológico, Brasília (DF): Ministério da Saúde; 2002.

7. World Health Organization. Joint United Nations Program HIV/AIDS (UNAIDS), 2001. AIDS epidemic update. Geneva: WHO; 2002.

8. UNAIDS, WHO. Guidelines for second generation HIV surveillance: the next decade. Geneva: WHO; 2000.

9. Ministério da saúde (BR). Coordenação Nacional de DST e AIDS. Vigilância do HIV no Brasil: novas diretrizes. Brasília (DF): Coordenação Nacional de DST e AIDS; 2002.

10. Silveira EAA, Carvalho AMP. Familiares de clientes acometidos pelo HIV/AIDS e o atendimento prestado em uma unidade ambulatorial. *Rev Latino-am de Enfermagem* 2002; 10(6): 813-8

11. Gazzinelli A. Convivendo com a doença crônica da criança: estratégias de enfrentamento. *Rev. Min. Enf* 1997; 1(1): 13-20.

12. Ministério da Saúde (BR). Conselho Nacional de Saúde. Comissão Nacional de Ética em Pesquisa-CONEP. Resolução nº 196/96. Diretrizes e Normas Regulamentadoras de Pesquisa envolvendo seres humanos. Brasília: Ministério da Saúde; 1996.

13. Bardin L. Análise de conteúdo. Lisboa: Edições 70; 1991.

14. Ministério da Saúde (BR). Boletim Epidemiológico, Brasília (DF): Ministério da Saúde; 1996/1997.
15. Ministério da Saúde (BR) Boletim Epidemiológico, Brasília (DF): Ministério da Saúde; 2003.
16. Ministério da Saúde (BR). Boletim Epidemiológico, Brasília (DF): Ministério da Saúde; 2000.
17. Borges NRAC. Mulheres e aids: refletindo sobre o risco. [Dissertação]. Campinas (SP): Faculdade de Educação. Universidade Estadual de Campinas; 2000.
18. Vieira NFC, Paiva TCH, Sherlock MSM. Sexualidade, DST/AIDS e Adolescência: não quero falar, tenho vergonha. DST-J Brs Doenças Sex Transm 2001; 13(4): 46-51.
19. Ministério da saúde (BR). Coordenação nacional de DST e AIDS. Aids no Brasil: um esforço conjunto governo-sociedade. Brasília (DF): Coordenação nacional de DST e AIDS; 1998.
20. Ministério da Saúde (BR). Boletim Epidemiológico, Brasília (DF): Ministério da Saúde; 1998.
21. Fonseca MGP, Travassos C, Bastos FI, Silva NV, Szwarcwald CL. Distribuição social da AIDS no Brasil, segundo participação no mercado de trabalho, ocupação e status sócio-econômico dos casos de 1987 a 1998. Cad. Saúde Pública 2003; 19(5): 1351-1363.
22. Stefani M, Araújo BF, Rocha NMP. Transmissão vertical do HIV em população de baixa renda do sul do Brasil. DST-J Bras Doenças Sex Transm 2004; 16(2): 33-39.
23. Diniz SG, Villela WV. Interfaces entre os programas de DST/AIDS e saúde reprodutiva: o caso brasileiro. In: Parker R, Galvão J, Bessa M. Saúde, Desenvolvimento e política-Resposta frente à AIDS no Brasil. Rio de Janeiro: Editora 34; 1999. p.123-176.
24. Vermelho LL. Mulheres com AIDS: Desvelando histórias de risco. Cad. Saúde Pública, 1999; 15:369-379.
25. Takahashi RF, Shima H, Souza M. Mulher e AIDS: perfil de uma população infectada e reflexões sobre suas implicações sociais. Rev. Latino – am. Enfermagem 1998; 6(5): 59-65.
26. Irvin N, Klaus MH, Kennel JH. Atendimento aos pais de um bebê com malformação congênita. In: Klaus MH, Kennel, JH. Pais/bebê: a formação do apego. Porto Alegre: Artes Médicas; 1992. p. 170-244.
27. Castro EK, Piccinini CA. A experiência de maternidade de mães de crianças com e sem doença crônica no segundo ano de vida. Estud. Psicol. (Natal) 2004; 9(1):89-99.
28. Bradford R. Children, families and chronic disease. Londres: Routledge; 1997.
29. Guimarães R, Ferraz AF. A interface AIDS, estigma e identidade – Algumas considerações. Rev. Min. Enf 2002; 6(1/2): 77-85.
30. Paiva V, Lima TN, Santos N, Ventura-Filipe E, Segurado A. Sem direito de amar? A vontade de ter filhos entre homens (e mulheres) vivendo com HIV. Psicol. USP 2002; 13(2):105-133.
31. Cazenave A, Ferrer X, Castro S, Cuevas S. El familiar cuidador de pacientes con SIDA y la toma de decisiones en salud. Revista Chilena de Infectología 2005; 22(1): 51 – 57.
32. Ferraz AF, Stefanelli MC. Interações familiares de pessoas vivendo com HIV e AIDS. Rev. Min. Enf 2001; 5(1/2): 52-59.

33. Salimena AMO, Cadete MMM. O medo como ameaça de perda: o vivido pela mãe diante da cirurgia do filho. *Rev Téc – cient Enferm* 2003; 1(2): 135-136.
34. Carvalho CML, Braga VAB, Galvão MTG. AIDS e Saúde Mental: Revisão Bibliográfica. *DST - J brás Doenças Sex Transm* 2004; 16(4):50-55.
35. Turne-Henson A, Holaday B, Corser N, Ogletree G, Swan JH. The experiences of discrimination: challenges for chronically ill children. *Pediatric Nurs* 1994; 20(6):571-577.
36. Garwick AW, Patterson JM, Bennett FC, Blum RW. Parent's perceptions of helpful vs unhelpful types of support in managing the care of preadolescents with chronic conditions. *Arch Pediatr Adolesc Med* 1998; 152:665-671.
37. Miller JF. *Coping with chronic illness: overcoming powerlessness*. Philadelphia: Davis; 1992.
38. Pinheiro MT. *O ser-mãe em seu viver com seu filho doente: uma perspectiva de desvelamento*. [Dissertação]. Rio de Janeiro (RJ): Escola de enfermagem Alfredo Pinto da UNIRIO, 1992.